23 — 24 JUNE 2022
INTERNATIONAL CONFERENCE

PEDIATRIC CANCERS & GENOMICS:
A GAME CHANGER?
Cross Perspectives Between Social Sciences, Medicine and Civil society

Amphithéâtre de Physique, Université Claude Bernard Lyon 1, Faculté de Médecine et de Pharmacie. 8, avenue Rockefeller, Lyon 8ème

cancerchildreng.sciencesconf.org
Day 1 : Thursday 23 June

9h30-10h15  Welcoming

10h30-  Inaugural Speech – Sylvain Besle (sociologist, CRCL, Dep. SHS CLB) and Nadège Corradini (pediatric oncologist, IHOPe)

10h45  Session 1 - Transformations of the frontier between care and research
Chair: Quentin Lade (sociologist & historian of sciences, Dep. SHS CLB, SIRIC LYRICAN)

- Childhood cancers and precision medicine: issues and perspectives - Gilles Vassal (pediatric oncologist, Gustave Roussy Comprehensive Cancer Center, Univ. Paris Saclay)
- Presenting the genomic activity of an oncopediatric department - Franck Bourdeaut (pediatric oncologist, SIREDO, centre d’oncologie pédiatrique de l’Institut Curie, INSERM U830)
- Should we keep on separating care and research in the context of genomics? - Catherine Dekeuwer (philosopher, MCF Faculté de philosophie, Univ. Lyon 3 Jean Moulin, IRPhil et SPHère - UMR 7219 et Univ. de Paris)

12h30-14h  Lunch break

14h-  Session 2 - Access to Genomics Medicine: inequalities, teamwork between medical specialties, new timelines of the disease
Chair: Juliette Froger-Lefebvre (sociologist, Univ. Paris Sorbonne, GEMASS, SIRIC, CURAMUS)

- A patients association's perspective - Patricia Blanc (president of Imagine for Margo association)
- Access to therapeutic innovation for Children, adolescents and young adults with advanced Cancer across Europe (ACCE project) - Solenne Carof (sociologist, Sorbonne Université-GEMASS) and Emilien Schultz (sociologist, CEPED, IRD, Univ. de Paris)
- Living with cancer/predisposition: whole genome sequencing in pediatric oncology - Ayo Wahlberg (anthropologist, Professor MSO, Univ. Copenhaguen)
- Trajectories of innovation in healthcare: bioethical and societal issues, a paradigm shift in care - Sophie Julia (geneticist, Génétique Médicale Hôpital Purpan CHU Toulouse, Inserm, UMR 1295, Equipe BIOETHICS)

15h45-16h15  Coffee break

16h15-  Session 3 - Political Stakes of Genomics Medicine
Chair: Héloïse Pillayre (sociologist, Dep. SHS CLB, SIRIC LYRICAN)

- Professionals, associations and representatives: teamwork in favor of research and children with cancer's families - Stéphanie Ville (Aidons Marina and Grandir Sans Cancer associations) and Stéphane Vedrenne (Eva pour la vie and Grandir Sans Cancer associations)
- Deploying genomic medicine in France through the 2025 Plan France Médecine Génomique - Frédérique Nowak (coordinator Plan France Médecine Génomique 2025)
- Planning genomic medicine in France in the era of high-speed bandwidth - Catherine Bourgain (sociologist, INSERM, Cermes3, CNRS UMR 8211, Inserm U988, EHESS, Univ. Paris Cité)
- Precision medicine delivery for paediatric cancer patients in the UK – current status, aspirations and challenges - Susanne GATZ (Associate Clinical Professor in Paediatric Oncology Cancer Research UK Clinical Trials Unit (CRCTU), Institute of Cancer and Genomic Sciences)
9h-9h10 Introduction to Day 2: presentation of a thematic issue of *Anthropologie et Santé* – Solenne Carof (sociologist, Sorbonne Université-GEMASS)

9h10-10h45 Session 4 - Envisioning Consent: Children's and their Families' Information and Choice
Chair: Alexandra Roux (sociologue, Iris, Univ. Paris-13, Cermes3)

*Ethical guidelines and regulations of biomedical research on children: between autonomy and vulnerability* - Maria Cristina Murano (philosopher, Institut de recherche biomédicale de l'hôpital La Paz, Hôpital universitaire La Paz, Univ. autonome de Madrid, SPHERE,CNRS-Univ. de Paris)

*Practices of pediatricians and interns in pediatric oncology: consent to research and communication of genetic information to parents and child – Conect-aml project* - Arnaud Petit (pediatric oncologist, Hopital Trousseau) and Audrey Guilmatre (clinical research engineer)

*GeneInfoKid project: psychological and ethical issues identified during the interviews and focus groups with parents and children* - Marion Droin-Mollard (psychologist, APHP) and Sandrine de Montgolfier (epistemologist et ethician of biomedical sciences, SESSTIM, Aix Marseille Univ./IPC)

*How to talk to children in an oncogenetic consultation* - Béatrice Claret (psychologist, IGR)

10h45-11h15 Coffee break

11h15-12h45 Session 5 - Data collection, conservation and re-use: juridical and ethical rules of genomic medicine
Chair: Marie Castets (biologist, CRCL)

*Reflections of parents' associations around data legal and ethical issues* - Catherine Vergely (ISIS-Unapecle association)

*Let's not forget the rights of children in oncogenetics: what the law says, or does not say...* - Emmanuelle Rial Sebbag (lawyer, CERPOP, UMR1295, Inserm/Univ. de Toulouse Paul Sabatier, team BIOETHICS, CERPOP)

*International discussions regarding return of results and secondary findings, leading to questions of re-analysis, duty to recontact, and consequences for family members* - Pascal Borry (professor of bioethics, Centre for Biomedical Ethics and Law, Dep.of Public Health and Primary Care, KU Leuven)

12h45-14h30 Lunch Break
14h30-16h15  Session 6 - Seize and Collect Sick Children’s voices
Chair: Solenn Thircuir (sociologist, Univ. Claude Bernard Lyon 1, Dep. SHS CLB)

Intergenerationality in the Pediatric Cancer Ward: Age-Based Power and the Production of Data about Children’s Voices - Anthony Wright (anthropologist, assistant Professor of Childhood Studies, Rutgers University)

There is no such thing as silence: Examining when young people with cancer do not talk (and neither do adults around them) - Ignasi Clemente (anthropologist, assistant Professor, City University of New York)

Capturing the experience of children with cancer from the first signs of the disease to post-cancer: issues and methodology - Hélène Lecompte (sociologist, SPHERE UMR INSERM 1246)

Between personalized medicine and medicine for the individual: the care of adolescents and young adults with cancer in France - Thibaud Pombet (sociologist, Institut Catholique de Paris, RCS, Cermes3, Lirtes)

16h15-16h30  Conclusion - Sandrine de Montgolfier

International conference with simultaneous translation (English/French & French/English)

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